

Posttraumatic Distress in Childhood Cancer Survivors and Their Parents

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INTRODUCTION

Significant advances in our understanding of the medical sequelae of treatment of childhood leukemia and other cancers have occurred. Potential medical and cognitive long-term complications of childhood cancer treatment are known to include problems with growth, puberty, cardiac and pulmonary functioning, second cancers, and intellectual abilities [1]. However, the psychological sequelae of this intense, intrusive, and often life-threatening experience for patients and their parents have not been identified adequately. These concerns are particularly salient given the recent, increasing attention devoted to the quality of life of survivors and the association of higher rates of cure with more aggressive treatments: That is, the processes and the ways in which psychological experiences and symptoms of survivors of childhood cancer and their parents contribute to, or detract from, successful transitions to young adult life require attention.

A series of studies of psychological adjustment published in the 1980s and early 1990s showed that survivors generally adjust well but that a significant subset continues to have ongoing difficulties [2]. These studies were ground breaking in documenting the general psychosocial functioning of survivors. Although in no way detracting from the significance of these studies, we are now in a position to improve some of the methodological difficulties in this earlier literature. These include very broad age ranges and lengths of time from diagnosis, nonrepresentative samples, lack of controlled studies, and early stages in the development of scales and instruments to assess the experiences of survivors and their families. For example, the use of standard, general measures of anxiety and depression may not capture distinctive aspects of surviving a life-threatening illness, including those that may be traumatic to children and parents.

Discussions of trauma in the context of illness have become more prevalent recently. "Learning that one's child has a life-threatening disease" is now included as a qualifying event for posttraumatic stress disorder (PTSD) in the Diagnostic and Statistical Manual of the American Psychiatric Association, version IV [3]. Although PTSD may be associated with childhood cancer diagnosis and treatment, symptoms and experiences of subdiagnostic posttraumatic stress (e.g., intrusive memories, avoidance, hypervigilance) are critical to

clarify the potential relationship between PTSD and serious illness.

Nir [4] first observed that children respond to cancer treatment as they do to other life-threatening situations. Others have concurred, observing posttraumatic stress in parents [5,6] and children who have completed bone marrow transplantation [7,8]. Many of the children were reported to avoid reminders of the cancer experience. A parallel literature in adult cancer is also emerging [9,10].

Family functioning and social support mechanisms represent important ways in which family adaptation to serious, chronic, pediatric illness can be understood [11]. Families of adolescent cancer survivors have been reported to be less flexible than families of healthy controls [12]. Other data suggest that the level of family functioning for survivor families was within the normative range, particularly when cognitive functioning and learning ability were unaffected by treatment [13]. The longitudinal research of Kupst and colleagues supports the notion that adaptive coping and social support throughout treatment predicts adjustment [14,15], with other recent studies highlighting the potential for isolation among parents and the importance of attending to family function in survivorship [16–18].

This study is a two-group design, comparing symptoms of anxiety and posttraumatic stress in survivors of childhood cancer and their parents with a comparison group of children and adolescents without chronic illness and their parents. To our knowledge, this is the first effort to include a comparison group in examining the prevalence of posttraumatic stress in childhood cancer survivors.

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This research was conducted at The Children's Hospital of Philadelphia and the University of California at Los Angeles, with Anne E. Kazak, Ph.D. (CHOP), and Margaret L. Stuber, M.D. (UCLA), as coprincipal investigators.

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vors. In addition, factors that influence the development of posttraumatic stress symptoms were examined. We hypothesized that survivors of childhood leukemia (8–20 years of age) and their mothers and fathers will report more symptoms of anxiety and posttraumatic stress than the comparison group. Exploratory analyses will be performed to examine additional factors that may contribute to and buffer against the development of posttraumatic stress symptoms, including child age, child age at diagnosis, and months off treatment. There is no specific hypothesis regarding these factors, because there is no prior literature on which to base assumptions.

MATERIALS AND METHODS

Sample Recruitment

English-speaking, pediatric leukemia patients 8–20 years of age who completed treatment at least 1 year previously and their parents were recruited from The Children's Hospital of Philadelphia (CHOP) and the University of California at Los Angeles (UCLA). A comparison group of children and adolescents with no chronic health problems and their parents was recruited from each site.

Leukemia survivors. A total of 313 eligible patients were identified through tumor registries: 231 at CHOP and 82 at UCLA. Of these, 52 (23%; CHOP) and 22 (27%; UCLA) could not be located, because no current address was available, reducing the potential sample to 239. Eligible former patients were sent a letter describing the study's goal to assess medical and psychological adjustment of cancer survivors. Of the families that were contacted for follow-up, 90% agreed to participate and were sent questionnaire packets. The reasons given by parents who declined included having participated in previous studies, not wanting to revisit painful events, and feeling that cancer was not relevant to them at present. The overall response rate was 61%. *T* tests and χ^2 analyses showed no significant differences between participants and nonparticipants on child current age, race, child age at diagnosis, diagnosis, months on treatment, months off treatment, treatment intensity, bone marrow transplant treatment, cranial radiation, or severity of medical late effects.

Comparison group. Comparison participants were recruited through hospital pediatric practices. Exclusion criteria were child or family member with serious, chronic, medical or psychiatric condition and/or lack of facility with English. Letters were sent describing the study as one that would examine the long-term psychological impact of being treated successfully for cancer and noting the importance of a comparison group. A follow-up phone call was made shortly thereafter to determine interest in participating in the study.

Participants

Leukemia survivors. The sample consists of 130 survivors (66 males, 64 females), 130 mothers, and 96 fathers from a total of 130 families. The patients ranged in age from 8 to 19 years [mean (*M*) = 13.45; standard deviation (*SD*) = 3.36] and had completed treatment a mean of 5.79 years prior to participation (*SD* = 3.14 years; see Table I). The majority (83.9%) had acute lymphoblastic leukemia (ALL), and 16.1% had acute non-lymphoblastic leukemia (ANLL). The mean age at diagnosis was 4.83 years (*SD* = 3.41; range, 1–16 years). Most of the survivors were white (90%), with 1% black, 5% Hispanic, and 4% Asian. Mean parental age was in the early 40s (*M*_{mothers} = 41.46 years, *SD* = 5.90; *M*_{fathers} = 44.11 years, *SD* = 6.26). Eighty-four percent were two-parent families. Nineteen percent reported annual incomes less than \$35,000, 55% reported incomes between \$35,000 and \$75,000, and 26% reported incomes over \$75,000.

Comparison group. The comparison sample consists of 155 children (71 males, 84 females), 148 mothers, and 80 fathers from 154 families. One child participated, but his/her parents did not. The children ranged in age from 8 to 20 years (*M* = 12.34, *SD* = 2.70; see Table I). Most of the participants were white (67%) with 15% black, 12% Hispanic, 5% Asian, and 1% other. Mean parental age was in the early 40s (*M*_{mothers} = 42.09 years, *SD* = 6.13; *M*_{fathers} = 43.82 years, *SD* = 6.75). Seventy-seven percent were two-parent families. Twenty-seven percent of families reported annual incomes under \$35,000, 28% reported incomes between \$35,000 and \$75,000, and 45% reported incomes over \$75,000.

Procedure

Questionnaires were mailed to leukemia survivors, comparison children, and the parents with whom they lived from October 1991 to August 1994. To assure anonymity and promote disclosure, individuals completed forms separately and sealed them in separate envelopes. All packets were returned in one postage-paid envelope, and families were sent \$10 for completing the study. The protocol was approved by the human-subject committees of both institutions.

Survivors and their parents responded based on their child's cancer and its treatment. Comparison families were asked to name a significant life stressor that affected the child, to note the date of the event, and to refer to it while completing the measures. Stressful events named by comparison families were weighted according to the system applied by the Life Events Scale [19] to reflect degree of impact. For all comparison families, scores ranged from 20 (e.g., starting at a new school) to 109 (e.g., death of a parent). The largest percentage re-

TABLE I. Group Comparisons on Selected Demographic Variables

| Variable | Survivor (n = 130) | Comparison (n = 154) | χ^2 | <i>p</i> |
|------------------------|-----------------------|-------------------------|----------------|----------|
| Race (%) | | | 26.81 (df = 4) | * |
| White | 90 | 67 | | |
| Black | 1 | 15 | | |
| Hispanic | 5 | 12 | | |
| Asian | 4 | 5 | | |
| Other | 0 | 1 | | |
| Education (%) | | | | |
| Mothers | | | 34.91 (df = 4) | * |
| High school or less | 30 | 10 | | |
| Some college | 36 | 27 | | |
| College graduate | 19 | 20 | | |
| Graduate school | 15 | 43 | | |
| Fathers | | | 38.13 (df = 3) | * |
| High school or less | 26 | 5 | | |
| Some college | 28 | 13 | | |
| College graduate | 29 | 23 | | |
| Graduate school | 17 | 59 | | |
| Income (%) | | | 36.52 (df = 7) | * |
| Less than \$20,000 | 7 | 19 | | |
| \$20–34,999 | 12 | 9 | | |
| \$35–49,999 | 26 | 9 | | |
| \$50–74,999 | 29 | 19 | | |
| \$75–99,999 | 13 | 11 | | |
| \$100–124,999 | 5 | 10 | | |
| Greater than \$125,000 | 8 | 23 | | |
| Child gender (%) | | | | |
| Female | 49 | 54 | 0.70 (df = 1) | |
| Male | 51 | 46 | | |
| Marital status (%) | | | 9.31 (df = 5) | |
| Married | 78 | 66 | | |
| Remarried | 6 | 10 | | |
| Divorced | 11 | 12 | | |
| Never married | 1 | 7 | | |
| Separated/widowed | 4 | 5 | | |

* $p < 0.001$. df, Degrees of freedom.

ported moderate-impact stressors with scores of 50–53: children = 43%, mothers = 61%, fathers = 62%. These moderate-impact events included child's accident, injury, or hospitalization; child threatened or hurt by someone; and child witnessed violence. Therefore, the majority of comparison family members responded to the measures based on moderate- to severe-impact stressors, which is a valid use of the measures.

A pediatric oncologist blind to patient identity rated all cancer survivors on a three point scale with regard to intensity of treatment and severity of medical late effects. Intensity is based on length of treatment, severity of expected treatment toxicities, and combinations of treatment modalities. Severity of medical late effects are coded based on limitation of activity, medical requirements and degree of cosmetic differences.

Measures

Impact of Event Scale. The Impact of Event Scale (IES) [20] consists of 15 items that are rated on a four-

point scale for frequency of occurrence during the previous week. It assesses two clusters of experiences that occur in response to a traumatic incident: intrusion and avoidance. The IES has high internal consistency and test-retest reliability, discriminates different populations and symptom levels, and has been supported by factor analysis [21] and in medical samples [22]. Norms are available for adult stress clinic patients [20] and for children who experienced a human-made disaster [23]. Due to positive skew, transformed scores were used in all analyses to increase variance by taking the square root of the value. Parents and children completed the IES.

State-Trait Anxiety Inventory. The State-Trait Anxiety Inventory (STAI) is a 40-item, self-report scale that assesses current and personality anxiety symptoms [24]. Test-retest reliability is low for the state scale and high for the trait scale, as predicted. The STAI has high internal consistency and adequate construct and discriminative validity across diverse samples [25]. Norms are available for stressed groups, general medical-surgical

TABLE II. Group Comparisons on Anxiety and Posttraumatic Stress Symptoms

| Group | Survivor | | Comparison | | <i>F</i> | <i>p</i> | Effect size |
|------------------------|----------|-------|------------|-------|----------|----------|-------------|
| | Mean | SD | Mean | SD | | | |
| Children | | | | | | | |
| IES intrusion | 5.13 | 6.31 | 4.62 | 6.30 | 1.35 | | 0.08 |
| IES avoidance | 6.80 | 7.80 | 6.94 | 8.32 | 1.76 | | 0.02 |
| IES total symptoms | 11.92 | 12.49 | 11.56 | 13.38 | 1.78 | | 0.03 |
| RCMAS/physical anxiety | 9.72 | 3.28 | 9.02 | 3.21 | 2.52 | | 0.22 |
| RCMAS/worry | 10.12 | 3.34 | 9.45 | 3.38 | 4.46 | * | 0.20 |
| RCMAS/social anxiety | 9.36 | 3.10 | 8.66 | 3.08 | 4.70 | * | 0.23 |
| RCMAS/total anxiety | 50.67 | 12.45 | 47.75 | 11.73 | 4.77 | * | 0.24 |
| Reaction Index | 13.39 | 11.13 | 13.48 | 10.22 | 0.83 | | 0.01 |
| Mothers | | | | | | | |
| IES intrusion | 8.24 | 8.31 | 4.92 | 7.04 | 4.10 | ** | 0.43 |
| IES avoidance | 7.66 | 8.91 | 4.74 | 7.29 | 2.88 | | 0.36 |
| IES total symptoms | 15.90 | 15.83 | 9.66 | 13.76 | 4.06 | ** | 0.42 |
| STAI/state anxiety | 36.50 | 12.40 | 35.31 | 12.61 | 3.21 | | 0.10 |
| STAI/trait anxiety | 38.51 | 10.17 | 37.80 | 9.50 | 3.26 | | 0.07 |
| Reaction Index | 23.14 | 13.58 | 16.07 | 11.44 | 6.30 | ** | 0.57 |
| Fathers | | | | | | | |
| IES intrusion | 6.41 | 7.79 | 1.65 | 3.88 | 4.50 | ** | 0.82 |
| IES avoidance | 5.03 | 7.53 | 1.78 | 7.53 | 3.71 | ** | 0.43 |
| IES total symptoms | 11.44 | 14.52 | 3.44 | 7.19 | 4.29 | ** | 0.74 |
| STAI/state anxiety | 34.41 | 10.65 | 33.49 | 11.56 | 1.43 | | 0.08 |
| STAI/trait anxiety | 34.65 | 9.31 | 34.28 | 8.16 | 1.08 | | 0.04 |
| Reaction Index | 20.23 | 13.32 | 13.38 | 8.78 | 4.78 | ** | 0.62 |

* $p < 0.001$.

** $p < 0.002$. IES, Impact of Events Scale; RCMAS, Revised Children's Manifest Anxiety Scale; STAI, State-Trait Anxiety Inventory.

patients, and new military recruits in basic training. The STAI was completed by the parents only.

Revised Children's Manifest Anxiety Scale The Revised Children's Manifest Anxiety Scale (RCMAS) is an established, 37-item, self-report inventory of trait anxiety in children [26] with three factors (physiological anxiety, worry and over-sensitivity; and concentration anxiety), with a total scale, and with a lie scale [27]. Internal consistency, test-retest reliability, and construct and discriminative validity are adequate [28]. The RCMAS was completed by the children only.

PTSD Reaction Index. The Reaction Index is a 20-item, self-report questionnaire that assesses symptoms of posttraumatic stress [29]. Items include intrusion, avoidance, and arousal. The scale has been used with children exposed to a variety of natural disasters and other traumatic events [30]. Data indicate a strong association of empirically derived categories with clinical diagnosis of PTSD based on diagnostic measures [31]. The categories are mild (12–24), moderate (25–39), and severe (>40). The frequency of each item is endorsed on a four-point scale, and the total score was used. Two items, which were stated in the reverse, were dropped from computation of children's total score, because all of the children had difficulty understanding these items. Parents and children completed this form.

RESULTS

Approach to Data Analysis

Despite the adequate sample size, concerns regarding type I error remain given the large number of analyses. The choice of alpha level was guided by the goal of minimizing the chance of type I error but not becoming stringent enough to risk type II error. The standard, conservative, alpha level of 0.01 was used for preliminary analyses and for all correlational analyses. Bonferroni corrections were applied in the multivariate analyses to control for experimentwise error. Due to this approach, the alpha level varies for each group of analyses. For a moderate effect size (0.5) at $p < 0.01$, the power for these analyses is 0.97. Effect sizes, reflecting the magnitude of the mean differences, are shown in Table II. Effect sizes greater than 0.5 are considered large: They indicate that the influence of group on posttraumatic stress symptoms is practically significant as well as statistically significant [32]. Effect sizes less than 0.3 are considered small.

Preliminary Analyses

Multivariate analyses of variance (MANOVAs) were computed to assess potential differences in the outcome variables between CHOP and UCLA. In light of the lack of site differences, the two samples were combined for all analyses. With the alpha level set at 0.01, the survivor

and comparison groups did not differ significantly on marital status, parent age, or child gender (see Table I). However, the comparison group had a wider minority representation ($\chi^2 = 26.81$; $p < 0.001$), a higher level of educational attainment ($\chi^2_{\text{mothers}} = 34.91$, $p < 0.01$; $\chi^2_{\text{fathers}} = 38.13$, $p < 0.001$), and higher annual income ($\chi^2 = 36.52$; $p < 0.001$) than the survivor group. The mean income for each group was in the middle income range. In terms of race, education, and income, both groups were representative of the populations from which they were sampled. In general, the comparison group was drawn from major metropolitan areas, whereas the survivor group came from a broader geographic area, including suburban and rural counties. Also, the children differed significantly in age ($t = -3.11$; $p < 0.01$), with the survivors being older than the comparison children by approximately 1 year (see Table I).

Group Comparisons on Anxiety and Posttraumatic Stress Symptoms

Multivariate analysis of covariance (MANCOVA) was used to assess differences between groups on anxiety and posttraumatic stress variables by using income, mother/father education, and race as covariates. Child age was also used as a covariate in the child analyses. Separate MANCOVAs were run for children, mothers, and fathers. Alpha was set at 0.01 for the multivariate tests. The Bonferroni correction was applied to the univariate tests, with the alpha level set at 0.001 for children and at 0.002 for parents. Also, anxiety and posttraumatic stress scores of each group were compared with scores for other stressed and traumatized groups by using t tests with the alpha level set at 0.01.

Children. Contrary to prediction, the overall test for significant differences and the test of effects for the education, income, and race covariates were not significant (see Table II). There was a significant effect for the child age covariate [$F(11, 229) = 3.87$; $p < 0.001$]. Examination of the univariate tests showed a significant difference between the groups on the anxiety variables of worry [$F(8, 239) = 4.46$; $p < 0.001$], social anxiety [$F(8, 239) = 4.70$; $p < 0.001$], and total anxiety [$F(8, 239) = 4.77$; $p < 0.001$] due to child age, indicating that there were group differences at certain age levels. Examination of mean scores on these anxiety measures at each age level suggested that the youngest survivor children reported higher anxiety than their comparison group counterparts. Effect sizes also indicate little influence of cancer diagnosis on posttraumatic stress symptoms.

Mothers. The test for overall group differences was significant [$F(6, 237) = 4.62$; $p < 0.001$; see Table II], supporting hypothesis 1. The tests for the effects of the three covariates were not significant. Examination of the univariate tests showed significant group differences be-

tween mothers of survivors and mothers of healthy children on all variables except IES avoidance and the state and trait anxiety variables. Thus, mothers of survivors had significantly higher IES intrusion symptoms [$F(7, 242) = 4.10$; $p < 0.002$], IES total symptoms [$F(7, 242) = 4.06$; $p < 0.002$], and posttraumatic stress symptoms on the reaction index [$F(7, 242) = 6.30$; $p < 0.002$]. Effect sizes reflected the moderate-to-large influence of survivor group membership on posttraumatic stress symptoms but not anxiety.

Fathers. Hypothesis 1 was supported, with a significant test for overall group differences [$F(6, 145) = 3.68$; $P < 0.001$; see Table II]. The tests for the effects of the three covariates were not significant. Examination of the univariate tests were similar to those for mothers. Fathers of survivors reported significantly higher levels of IES intrusion symptoms [$F(7, 150) = 4.50$; $p < 0.002$], IES avoidance symptoms [$F(7, 150) = 3.71$; $p < 0.002$], IES total symptoms [$F(7, 150) = 4.29$; $p < 0.002$], and the Reaction Index posttraumatic stress symptoms [$F(7, 150) = 4.78$; $p < 0.002$] than fathers of healthy children. State and trait anxiety did not differ between the fathers. Effect sizes showed the moderate-to-large magnitude of differences between group scores on posttraumatic stress symptoms.

Associations With Diagnoses of PTSD

Scores in the moderate and severe ranges on the Reaction Index have been associated with independent diagnosis of PTSD. Of the survivor children, 1.6%, and 1.4% of children in the comparison group had posttraumatic stress symptom scores in the severe range (a total score of 40 or more), and 12.6% of survivor children and 14% of comparison children had scores in the moderate range [a total score of 25–39; $\chi^2(4; n = 274) = 1.47$; not significant]. The level of posttraumatic stress symptoms reported by mothers of survivors placed 10.2% of them in the severe range of the Reaction Index, which was significantly more than the 2.8% of mothers of healthy children who scored in this range. Thirty percent of survivor mothers and 19.6% of comparison mothers had scores in the moderate range [$\chi^2(4; n = 272) = 16.82$; $p < 0.001$]. For fathers of survivors, 9.8% scored in the severe range of posttraumatic stress symptoms on the Reaction Index, whereas no fathers of healthy children did. For the moderate range, 21.4% of survivor fathers and 13% of comparison fathers had scores in this range. This group difference was statistically significant [$\chi^2(4; n = 171) = 11.05$; $p = 0.011$].

Comparisons With Other Traumatized Samples

A series of t tests were computed to compare posttraumatic stress symptoms reported by the survivor and comparison group children to scores for other trauma-

TABLE III. Comparison of Survivor and Comparison Groups With Stressed/Traumatized Groups†

| Group | Survivor X (SD) | Comparison X (SD) | Stressed/traumatized X (SD) |
|--------------------|--------------------|----------------------|--------------------------------|
| Children | | | |
| Girls | | | |
| IES intrusion | 6.13 (7.02)* | 5.00 (6.74)* | 18.21 (9.77) |
| IES avoidance | 7.37 (8.24)* | 6.87 (8.25)* | 18.24 (10.25) |
| IES total | 13.49 (13.53)* | 11.87 (13.79)* | 36.44 (17.61) |
| Reaction Index | 17.25 (12.82)* | 14.27 (10.86)* | 52.60 (8.40) |
| Boys | | | |
| IES intrusion | 4.15 (5.41)* | 4.11 (5.71)* | 15.03 (11.45) |
| IES avoidance | 6.26 (7.77)* | 7.05 (8.46)* | 14.32 (11.09) |
| IES total | 13.49 (13.53)* | 11.16 (12.93)* | 29.34 (20.95) |
| Reaction Index | 9.59 (7.52)* | 12.46 (9.32)* | 52.60 (8.40) |
| Mothers | | | |
| IES intrusion | 8.24 (8.31)* | 4.92 (7.04)* | 21.40 (8.60) |
| IES avoidance | 7.66 (8.91)* | 4.74 (7.29)* | 20.60 (11.30) |
| IES total | 15.90 (15.83)* | 9.66 (13.76)* | 42.10 (16.70) |
| STAI/state anxiety | 36.98 (12.56)* | 35.26 (12.53)* | 47.01 (14.42) |
| STAI/trait anxiety | 38.62 (10.27) | 37.76 (9.38)* | 43.10 (12.55) |
| Reaction Index | 23.15 (13.58)* | 16.07 (11.44)* | 46.00 (10.60) |
| Fathers | | | |
| IES intrusion | 6.41 (7.79)* | 1.65 (3.88)* | 21.20 (12.50) |
| IES avoidance | 5.03 (7.53)* | 1.78 (7.53)* | 14.10 (11.30) |
| IES total | 11.44 (14.52)* | 3.44 (7.19)* | 35.30 (22.60) |
| STAI/state anxiety | 34.23 (10.83)* | 33.65 (11.69)* | 44.05 (12.18) |
| STAI/trait anxiety | 34.75 (9.63)* | 34.74 (8.03)* | 43.10 (12.55) |
| Reaction Index | 20.23 (13.31)* | 13.37 (8.78)* | 46.00 (10.60) |

IES, Impact of Events Scale; TSC, Trauma Symptom Checklist; STAI, State-Trait Anxiety Inventory. Data were obtained from the following: for *children*, IES [23] and Reaction Index [31]; and for *parents*, IES [20], STAI [24], and Reaction Index (Goenjian et al., 1994). Insufficient data were available for the RCMAS, although scores for both groups revealed group means that hovered around the standard and T-score means.

* $p < 0.01$.

tized groups. Generally, survivor children scores were significantly lower ($p < 0.01$) than those reported for stressed and traumatized groups (see Table III). Similar results were found for the comparison group. From t tests, survivor and comparison group levels of anxiety and posttraumatic stress for mothers and fathers were significantly lower ($p < 0.01$) than symptom levels found for other stressed and traumatized groups (Table III), with the exception of trait anxiety for survivor mothers (see Table III).

Intercorrelations Among Child Age, Child Age at Diagnosis, and Months Off Treatment With Posttraumatic Stress Symptoms and Anxiety

For the survivor group, younger child age, age at diagnosis, and greater months off treatment generally did not show strong patterns of association. Child age was correlated significantly with father IES avoidance ($r = -0.26$; $p < 0.01$). Months off treatment was related negatively to all three father IES variables (avoidance: $r_{\text{avd}} = -0.26$, $p < 0.01$; intrusion: $r_{\text{int}} = -0.29$, $p < 0.01$; and total symptoms: $r_{\text{tot}} = -0.29$, $p < 0.001$). No significant correlations were found for mothers.

For the comparison group children, child age was correlated significantly with all four anxiety subscales [physical anxiety: $r_{\text{phy}} = 0.25$, $p < 0.01$; worry: $r_{\text{worry}} = 0.27$, $p < 0.001$; social anxiety: $r_{\text{soc}} = 0.34$, $p < 0.001$; and total anxiety: $r_{\text{tot}} = 0.29$, $p < 0.001$] and with Trauma Symptom Checklist (TSC) traumatic stress. This indicates that, with increasing age, comparison children were more likely to endorse symptoms of anxiety and posttraumatic stress. However, mother and father reports of anxiety and posttraumatic stress symptoms were not correlated significantly with child age.

DISCUSSION

These results shed new light on the often perplexing picture of childhood cancer survivors and their families who, despite good overall adjustment, report ongoing difficulties, concerns, and anxieties. The addition of serious illness to the DSM IV [3] as a qualifying traumatic event for PTSD shows that psychological difficulties associated with illness have been revisited. However, the lack of a database with which to evaluate the empirical relevance of posttraumatic stress has been problematic.

The data presented offer a promising perspective on the importance of posttraumatic stress for understanding the ongoing psychological sequelae experienced by parents of survivors. That is, we found significantly elevated posttraumatic stress symptoms in mothers and fathers of childhood cancer survivors compared with parents of children who had never been ill. Moreover, the rate of symptoms in the severe range for survivor parents (10.2% for mothers and 9.8% for fathers) is comparable to prevalence statistics for PTSD despite the finding that scores were significantly lower than other stressed and traumatized groups. It has been reported that those who develop PTSD include between 3% and 58% of at-risk individuals [3], 1% of the general population, 3.5% of persons experiencing physical assaults, and 20% of war veterans [33]. It is significant that these data support the adaptability of childhood cancer survivors and their parents. There were no differences between the survivors themselves and the comparison children in level of posttraumatic stress symptoms.

The diagnosis of cancer in an individual's child is accepted as one of the most severe stressors that parents can experience. These data indicate that the psychological reactions to diagnosis and treatment often continue in a chronic, subdiagnostic course of intrusive memories and flashbacks about cancer and its treatment. The symptoms may be relatively frequent and bothersome to mothers and fathers alike. In fact, when they were asked questions about specific experiences of posttraumatic stress symptoms, parents indicated interference with daily living to the extent that fears resurface and memories intrude, even in response to such common occurrences as childhood colds, aches, and pains. Despite this interference, parents and their families are not functionally impeded significantly. It is also possible that this study underestimates the prevalence of posttraumatic stress symptoms, because nonparticipation in the study could be related to avoidance, which is a posttraumatic stress symptom itself.

Nevertheless, the implications are notable for the impact of the parents' distress on both the parents' and the families' long-term adjustment. These mothers and fathers continue to shape their children's experiences and the overall functioning of the family. The long-term implications for children understanding of the illness and overall adjustment (both former patients and their siblings) while parents experience ongoing posttraumatic stress symptoms are potentially powerful.

The importance of understanding symptoms of posttraumatic stress in more detail is clearly warranted. Although it is highly correlated with the posttraumatic stress outcome variables, anxiety did not differ between groups. This suggests that anxiety may be a mediating variable with a parent's trait anxiety, determining to some extent the way in which the cancer experience is

understood and responded to. Parents indicated that learning that their child had cancer, procedures, and seeing other children who died remain vivid in their memories. The identification of specific aspects of cancer diagnosis and treatment that are traumatogenic by assessing the content of intrusive images (e.g., procedures), objects of avoidance (e.g., hospitals), and cognitions regarding life threat, relapse, and change due to treatment are needed. In identifying these aspects, interventions may be developed and implemented at the time of treatment that may reduce the immediate impact of these specific aspects and protect against long-term sequelae. In addition, interventions for parents after treatment ends are indicated in light of these data. For parents, having the opportunity to discuss ongoing psychological concerns that postdate cure may validate and reduce their often under-appreciated psychological sequelae.

In contrast to parents, the cancer survivors did not differ from the comparison participants in self-reported posttraumatic stress symptoms. These data are contrary to prediction and warrant further consideration. There are several possible explanations for the lack of symptoms in former patients. One explanation is the inherent difference in the types of events that the two groups experienced. There is the question of the extent to which survivors can actually recall having cancer. With a median age of onset of leukemia of 3–4 years, many survivors will have few specific memories of their treatment. In contrast, by design, comparison participants named events for which their memory was obviously operative. This presents a methodological challenge. Also, there may be biases in the selection of comparison participants (e.g., do families that volunteer for a research project have more stressors than a general community sample?). The comparison-group children named events that were most often of moderately stressful impact, such as being threatened by violence.

In a related vein, the relationships between a child's current age and age at diagnosis and a child's posttraumatic stress symptoms were not significant, indicating that endorsement of traumatic memories was only mild to moderate, regardless of the age of the child at the time of diagnosis and treatment. Perhaps the limited ability of preschool and school-age children to process cognitively the life threat of the cancer serves to protect them against the full impact of this trauma. Alternatively, there may be undetected ways in which children process trauma differently from adults or facets of trauma that are unique in illness. Further research that will broaden the age range to include those diagnosed in adolescence and young adulthood and the types of cancer (or other illnesses) may facilitate our understanding of the developmental impact. The experience of children who have had treatments of varying intensities and severities of medical sequelae deserves investigation.

Finally, the current phase of instrumentation for assessing posttraumatic stress symptoms in children requires comment. Existing scales were developed to assess acute events rather than the long-term effect of stressors, such as serious childhood illness. These scales are based on symptoms that are seen primarily in children who are exposed to violence or natural disasters. Refinement of measures may help in understanding illness-specific aspects of trauma sequelae. Questions about memories of young children need to include a developmentally appropriate methodology in order to determine precisely what is recalled and which aspects of these memories are associated with posttraumatic symptoms.

Despite these explanations, the lack of differences remains an important and perplexing finding. It suggests that assumptions of posttraumatic stress in childhood cancer survivors should be viewed cautiously and investigated further. However, given the parental findings, the lack of group differences should not be trivialized or seen as dismissive of posttraumatic stress symptoms in survivors in light of the noted difficulties imposed by the study design and the potential contribution of posttraumatic stress for understanding stress in this population.

The use of a comparison group does add a degree of methodological rigor that was missing previously in the related literature. Particularly in light of the need to use relatively new measures for assessing posttraumatic stress, the use of a referent group appears helpful. However, the difficulties inherent in this design also loom significantly. It is challenging to recruit representative comparison groups, and statistical approaches (e.g., covariance analyses) provide statistical control for group differences but obviously cannot alter inherent group differences. For example, important, inherent differences between the groups (e.g., having had a serious medical condition) raise questions about the applicability of this model. That is, research questions geared toward understanding why some affected families do well, whereas others experience greater difficulties, remain paramount. In the case of posttraumatic stress, relevant questions concern further identification and refinement of the aspects of childhood cancer and its treatment, which are most likely to be recalled traumatically. This can inform the design and evaluation of psychological interventions (both during cancer treatment and after cancer treatment ends) and can establish efficacy in decreasing long-term psychological sequelae of cancer and its treatment.

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REFERENCES

1. Meister L, Meadows A: Late effects of childhood cancer treatment. *Curr Prob Pediatr* 23:102-131, 1993.
2. Kazak AE: Implications of survival: Pediatric oncology patients and their families. In Bearison D, Mulhern R (eds): "Pediatric Psychooncology: Psychological Perspectives on Children With Cancer." New York: Oxford University Press, 1994, pp. 171-192.
3. American Psychiatric Association: "Diagnostic and Statistical Manual of the American Psychiatric Association." Washington, DC: American Psychiatric Association Press, 1994.
4. Nir Y: Post traumatic stress disorder in children with cancer. In Eth S, Pynoos R (eds): "Post Traumatic Stress Disorders in Children." Washington, DC: American Psychiatric Association Press, 1985, pp. 123-132.
5. Pelcovitz D, Goldenberg B, Kaplan S, et al.: Posttraumatic stress disorders in mothers of pediatric cancer survivors. *Psychosomatics* 37:116-126, 1996.
6. Heiney S, Neuberg R, Myers D, et al.: The aftermath of bone marrow transplant for parents of pediatric patients. *Oncol Nursing Forum* 21:843-847, 1994.
7. Pot-Mees C: "The Psychosocial Effects of Bone Marrow Transplantation in Children." Amsterdam: Eubron Delft, 1989.
8. Stuber M, Nader K, Yasuda P, et al.: Stress responses following pediatric bone marrow transplantation: Preliminary results of a prospective longitudinal study. *J Am Acad Child Adolesc Psychiatr* 30:952-957, 1991.
9. Alter C, Pelcovitz D, Axelrod A, et al.: Identification of PTSD in cancer survivors. *Psychosomatics* 37:137-143, 1996.
10. Cordova M, Andrykowski M, Kenady D, et al.: Frequency and correlates of posttraumatic stress disorder like symptoms after treatment for breast cancer. *J Consult Clin Psychol* 63:981-986, 1995.
11. Kazak AE: Families of chronically ill children: A systems and social ecological model of adaptation and challenge. *J Consult Clin Psychol* 57:25-30, 1989.
12. Madan-Swain A, Brown R, Sexson S, et al.: Adolescent cancer survivors: Psychosocial and familial adaptation. *Psychosomatics* 35:453-459, 1994.
13. Kazak AE, Christakis D, Alderfer M, et al.: Young adolescent cancer survivors and their parents: Adjustment, learning problems, and gender. *J Family Psychol* 8:74-84, 1994.
14. Kupst MJ, Schulman J: Long-term coping with pediatric leukemia. *J Pediatr Psychol* 13:7-22, 1988.
15. Kupst MJ, Natta M, Richardson C, et al.: Family coping with pediatric leukemia: Ten years after treatment. *J Pediatr Psychol* 20:601-618, 1995.
16. Rait D, Ostroff J, Smith K, et al.: Lives in a balance: Perceived family functioning and the psychosocial adjustment of adolescent cancer survivors. *Family Process* 31:383-397, 1992.
17. Ostroff J, Steinglass P: Psychosocial adaptation following treatment: A family systems perspective on childhood cancer survivorship. In Baider L, Cooper C, Kaplan-DeNour A (eds): "Cancer and the Family." New York: Wiley-Liss, Inc., 1995, pp. 127-145.
18. Van Dongen-Melman J, Pruyn J, De Groot A, et al.: Late psychosocial consequences for parents of children who survived cancer. *J Pediatr Psychol* 20:567-586, 1995.
19. Coddington R: The significance of life events as etiologic factors in diseases of children II: A study of a normal population. *J Psychosom Res* 16:205-213, 1972.
20. Horowitz M, Wilner N, Alvarez W: Impact of Event Scale: A measure of subjective stress. *Psychosom Med* 41:209-218, 1979.
21. Schwarzwald J, Solomon Z, Weisenberg M, et al.: Validation of the Impact of Event Scale for psychological sequelae of combat. *J Consult Clin Psychol* 55:251-256, 1987.
22. Epping-Jordan J, Compas B, Howell D: Predictors of cancer pro-

- gression in young adult men and women: Avoidance, intrusive thoughts, and psychological symptoms. *Health Psychol* 13:539–547, 1994.
23. Yule, W: Post traumatic stress disorder in child survivors of shipping disasters: The sinking of the “Jupiter.” *Psychother Psychosom* 57:200–205, 1992.
 24. Spielberger C: “Manual for the State-Trait Anxiety Inventory (Form Y).” Palo Alto, CA: Consulting Psychologists Press, 1983.
 25. Novy D, Nelson D, Goodwin J, et al.: Psychometric comparability of the State-Trait Anxiety Inventory for different ethnic subpopulations. *Psychol Assess* 5:343–9, 1993.
 26. Reynolds C, Richmond B: “Manual for the Revised Children’s Manifest Anxiety Scale.” Los Angeles, CA: Western Psychological Services, 1985.
 27. Reynolds C, Paget K: Factor analysis of the Revised Children’s Manifest Anxiety Scale for blacks, whites, males and females with a national normative sample. *J Consult Clin Psychol* 49:352–359, 1981.
 28. Perrin S, Last C: Do childhood anxiety measures measure anxiety? *J Abnorm Child Psychol* 20:567–578, 1992.
 29. Pynoos R, Frederick C, Nader K, et al.: Life threat and post traumatic stress in school age children. *Arch Gen Psychiatr* 4: 1057–1063, 1987.
 30. Lonigan C, Shannon MT, Finch A, et al.: Children exposed to disaster: II. Risk factors for the development of post traumatic symptomatology. *J Am Acad Child Adolesc Psychiatr* 33:94–105, 1994.
 31. Pynoos R, Goenjian A, Tashjian M, et al.: Post traumatic stress reactions in children after the 1988 Armenian earthquake. *Br J Psychiatr* 163:239–247, 1993.
 32. Cohen J: “Statistical Power Analysis for the Behavioral Sciences, 2nd Ed.” Hillsdale, NJ: Lawrence Erlbaum, 1988.
 33. Helzer J, Robins L, McEvoy L: Post traumatic stress disorder in the general population: Findings of the Epidemiological Catchment Area survey. *New Engl J Med* 317:1630–1634, 1987.